

## Sex, gender, and medical data

**Susan Bewley, Margaret McCartney, Catherine Meads, Amy Rogers**

We need to understand the difference between sex and gender.

Sex and gender are not synonymous. Sex, unless otherwise specified, relates to biology: the gametes, chromosomes, hormones and reproductive organs. Gender relates to societal roles, behaviours and expectations that vary with time and place, historically and geographically. These categories describe different attributes that must be considered depending on the purpose they are intended for.<sup>1</sup> The World Health Organisation states, “Gender is used to describe the characteristics of women and men that are socially constructed, while sex refers to those that are biologically determined”.<sup>2</sup> However, contemporary medical research and clinical practice often erroneously use ‘sex’ and ‘gender’ interchangeably. Further, there are other categories, again with distinct purposes. UK law allows registered sex on a birth certificate to be changed on the issue of a Gender Recognition Certificate (GRC); this certificate, of legal sex, requires approval by a committee, and no medical intervention. Administrative sex categories such as those recorded in passports or NHS numbers can be changed from female to male, or vice versa, on request.<sup>3</sup>

The right question must be asked to obtain the information desired; recent debate around the 2021 census in England has drawn public attention to classification issues.<sup>4</sup> The Office of National Statistics (ONS), in discussion with stakeholders, recognised that previously the census question, which asked ‘are you male or female’ (without accompanying guidance), was insufficient to provide quality information for service planning and equality monitoring. Data is being collected on sex (as a mandatory question with two answers) and gender identity (as a voluntary question and freetext) in the March 2021 England and Wales census.<sup>5</sup> However, the accompanying guidance did not clearly explain whether the sex data being sought was legal sex as recorded on a Birth or Gender Recognition Certificate, sex as recorded on other administrative documents such as passport or NHS records, or biological sex.

Subsequently, a legal challenge has resulted in a change to the advice accompanying the ONS question. Individuals will now be asked their sex according to their Birth or Gender Recognition Certificate, followed by questions on gender identity. In Scotland, the national statistician is currently consulting on the 2022 Census wording of sex and gender questions, proposing the converse of England and Wales: a compulsory gender identity question, but a voluntary question disclosing legal sex.<sup>6</sup>

Medical care requires an understanding of the difference between sex and gender categories; untangling them is crucial for safe, dignified, and effective healthcare of all groups. Avoidable harm may result when they are conflated; for example, if sex-specific laboratory reference ranges are used for people whose gender is recorded but not their biological sex.<sup>7-9</sup> Further, assuming that a patient’s recorded sex equals their gender creates problems for people who do not ascribe to or identify with socially constructed gender roles. Sex- and gender-disaggregated data are necessary to ensure that public services are organised for the whole population, not just the majority. Finally, confidentiality and respect for all groups are essential to ensure safety in reporting and ensure that data available are as accurate as possible and can be used to benefit all groups.

The Royal College of General Practitioners already recommends that sex and gender markers are separated in medical records<sup>10</sup>, but standard NHS systems do not allow for this. The NHS number - a personal, life-long identifier given at birth - codes people by biological sex (in Scotland: odd numbers for male, even numbers for female). In turn, this drives sex-specific automated screening invitations

(cervical, breast, and aortic aneurysm) and laboratory reference ranges. The administrative process of changing NHS numbers, which many trans and non-binary people choose, will then effectively make the NHS number a gender marker, not a sex marker, and thus may result in relevant information about biological sex being out of reach to healthcare practitioners, researchers and administrators.

A recent comprehensive review showed how personal and environmental factors make sex and gender powerful risk factors for virtually every disease and organ.<sup>11</sup> Sex differences in drug metabolism are increasingly well recognised, but gender can also significantly affect how individuals experience healthcare and engage with treatment. Research reporting guidelines already recommend that authors “should use the terms sex and gender carefully in order to avoid confusing both terms”.<sup>12</sup> New tools, such as IGAR (Integrating Gender Analysis into Research), go further in recommending that researchers “include explicit definitions of sex and gender” when planning research studies and applying for funding<sup>13</sup>; this requires researchers to plan whether they need information about sex, gender or both and design their studies accordingly.

Asking the right questions is vital. Disaggregated data can inform new hypotheses and enable better decision making. For example, a lack of inquiry means there is no accurate data or high-quality evidence on whether gender diverse people are more or less affected by Covid-19, and thus whether public health and medical advice ought to be different for trans people taking cross-sex hormones.

Anyone using data primarily collected for another purpose, e.g. clinical researchers using NHS or census datasets, need to understand the original purpose and mode of data collection. Ambiguous data collection methods that conflate sex and gender categories risk erroneous research findings, poor service planning, and lower quality medical practice. Gender and sex should not be used interchangeably. We risk harming patients unless we understand the difference.

## References

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